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STUDY PROTOCOL

Co-creation of web-based informational content for support network members of childhood, adolescent and young adult cancer survivors: A mixed-methods study protocol of the e-QuoL content creation project

[version 1; peer review: awaiting peer review]

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v1 **First published:** 10 Sep 2026, **6**:345
https://doi.org/10.12688/openreseurope.24667.1
Latest published: 10 Sep 2026, **6**:345
https://doi.org/10.12688/openreseurope.24667.1

Abstract

Introduction

Support network members of childhood, adolescent, and young adult cancer survivors (CAYACS)—including relatives and other close individuals—report substantial unmet information and support needs. Yet, no central, tailored resource is currently available in Europe. This project, part of the European e-QuoL (e-health tools to promote Equality in Quality of Life) initiative, aims to develop multilingual, evidence-based, online informational content for support network members to promote their long-term well-being. This paper describes the co-creation methods used to develop this informational content.

Methods

We followed a four-phase co-creation process (2024–2027). *Phase 1* identified key topics through systematic reviews and the European e-QuoL Needs Study. *Phase 2* involved drafting informational content by experts in pediatric oncology, psychosocial care, and survivorship,

Open Peer Review

Approval Status *AWAITING PEER REVIEW*

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written in accessible language (Hemingway grade ≤ 9), followed by focus groups and interviews with support network members to evaluate its relevance, clarity, completeness, and helpfulness. Eligible participants were aged ≥16 years, English-speaking, and living in Europe. *Phase 3* consisted of a Delphi study with experts and support network members to iteratively refine the content until ≥75% consensus was reached. *Phase 4* involves translation, country-specific adaptation, and dissemination through the PanCare website.

Results

Support network members reported needs spanning multiple domains, including cancer-related health information, psycho-emotional support, follow-up care, finances, education, and sexuality. In total, 13 support network members participated in focus groups and interviews, and 52 experts and support network members participated in the Delphi study, in which consensus was reached in two rounds.

Discussion

This project provides a central, multilingual, evidence-based online information resource for support network members of CAYACS. The co-creation approach enhances information quality and user relevance, while broad dissemination via the PanCare website, in multiple languages, promotes accessibility. Beyond its practical outcomes, the study contributes to scientific knowledge on co-creation and user-centered design in survivorship research.

Keywords
Childhood, adolescent and young adult cancer survivors (CAYACS), Co-creation, Delphi Study, Focus groups, Information and support needs, Support network members, Web-based information

HE This article is included in the Horizon Europe gateway.

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Author roles: Maas A: Conceptualization, Writing – Original Draft Preparation; **Balaeva V**: Conceptualization, Writing – Review & Editing; **Roganovic J**: Funding Acquisition, Writing – Review & Editing; **Demoor-Goldschmidt C**: Funding Acquisition, Writing – Review & Editing; **Lie H**: Conceptualization, Funding Acquisition, Writing – Review & Editing; **Thornton K**: Conceptualization, Writing – Review & Editing; **Roser K**: Conceptualization, Writing – Review & Editing; **Michel G**: Conceptualization, Funding Acquisition, Supervision, Writing – Review & Editing

Competing interests: No competing interests were disclosed.

Grant information: This project has received funding from the European Union's Horizon Europe Research and Innovation Programme under Grant Agreement No. 101136549 (e-QuoL), and Swiss State Secretariat for Education, Research and Innovation (SERI) under Reference No. REF-1131-52105 (e-QuoL project).
The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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How to cite this article: Maas A, Balaeva V, Roganovic J *et al.* **Co-creation of web-based informational content for support network members of childhood, adolescent and young adult cancer survivors: A mixed-methods study protocol of the e-QuoL content creation project [version 1; peer review: awaiting peer review]** Open Research Europe 2026, **6**:345
https://doi.org/10.12688/openreseurope.24667.1

First published: 10 Sep 2026, **6**:345 https://doi.org/10.12688/openreseurope.24667.1

List of abbreviations

AI: Artificial Intelligence
CAYACS: Childhood, Adolescent And Young Adult Cancer Survivors
CCI Europe: Childhood Cancer International - Europe
e-QuoL: e-Health Tools to Promote Equality in Quality of Life for Childhood to Young Adulthood Cancer Patients, Survivors and their Families
IGHG: International Guideline Harmonization Group
LTFU: Long-Term Follow-Up
QR: Quick Response

1. Introduction

The diagnosis of cancer in a child, adolescent, or young adult profoundly affects not only the individual but also their support network, including parents, partners, siblings, grandparents, and other close relatives, and friends.[1–4] Survivors of childhood, adolescent, and young adult cancer (CAYACS) remain at increased risk for physical and psychosocial late effects resulting from the disease and its treatment.[5–8] In this context, CAYACS and their support network often face a wide range of information and support needs, even in long-term survivorship.[9,10]

Previous research has shown that support network members experience substantial unmet information and support needs across multiple domains, including cancer-related health information, psycho-emotional support, follow-up care, education, and employment.[9,10] These findings demonstrate the need for a central, evidence-based information resource. Moreover, disparities in access to information and follow-up care persist across Europe, highlighting inequities that may affect the long-term well-being of CAYACS and their support networks.[11]

The format in which information is provided also plays a critical role. Support network members have reported a preference for written information,[9,10] which allows them to access information at their own pace and at times of personal relevance.[12–14] Evidence from both qualitative and quantitative systematic reviews indicates that written resources can reduce unmet information needs and support coping among support network members of CAYACS.[9,10] A multilingual, centralized online resource could therefore improve access to evidence-based information while reducing the need to navigate multiple websites to find reliable content.[15]

Against this background, the present project aims to develop multilingual, evidence-based, web-based informational content tailored to the needs of the support network members of CAYACS across Europe. Existing organizations, such as PanCare, provide evidence-based information and survivorship resources for CAYACS.[16] Building on these existing resources, this project focuses specifically on the broader support network of CAYACS by developing multilingual informational content.

To ensure that the information is tailored to the target group, the project follows a co-creation approach. Support network members provided information on their needs via a questionnaire,[17] and feedback on the informational content through focus groups. Together with experts in the field, they also evaluated the quality of the content in a Delphi study.[18] Co-creation approaches have been shown to offer a wide range of benefits, including increased user satisfaction, higher quality of outputs, and a better fit between content and users' needs.[19]

This project is part of the e-QuoL (e-health tools to promote Equality in Quality of Life for childhood to young adulthood cancer patients, survivors and their families) initiative, which develops e-health tools in collaboration with CAYACS and their support network members to promote their well-being.[20] Further information is available at www.equolproject.eu. While the broader e-QuoL initiative also addresses the information and support needs of CAYACS themselves, the present project specifically focuses on their support network members, who face distinct needs of their own and play a vital role in CAYACS' long-term well-being.[21]

The final informational content will be hosted on the PanCare website[16] (www.pancare.eu). By providing accessible, evidence-based information on a broad range of topics through one central online platform, this project has the potential to reduce inequalities in access to information across Europe and enhance long-term support for CAYACS and their support network.

2. Methods

2.1 Aims

The primary aim of this project was to develop multilingual, evidence-based informational content addressing the unmet information and support needs of support network members of CAYACS across Europe, including parents, partners, siblings, peers, and other significant individuals in the lives of CAYACS.

Table 1. Key characteristics of the informational content.

Key characteristic	Description	Implementation
Accessible	Available in multiple European languages and formats, written in easy-to-read language	Translation into ≥10 languages, plain-language editing (Hemingway grade ≤ 9[23]), use of text, fact sheets, and videos
Co-created	Developed by experts and refined with support network members and external experts	Focus groups and Delphi study
Comprehensive	Wide range of topics relevant for support network members (e.g., health, psycho-emotional care, follow-up, finances, education, sexuality)[9,10,17]	Informational content was developed for each domain in which information and support needs were identified[9,10,17]
Evidence-based	Based on systematic reviews and peer-reviewed studies	Systematic literature searches on each topic prior to the creation of informational content
Generic and country-specific	Combines general European-level content with national resources	European-level content and country-specific links to resources (e.g., late effects clinics, patient organizations, professional support)
Web-based	Hosted on a well-known platform	Integration of the informational content into the PanCare website[16]

The informational content was designed around six key characteristics defined a priori by the multidisciplinary e-QuoL consortium. These characteristics were informed by existing evidence on the information and support needs of support network members[9,10] and by the project's objective of developing accessible, multilingual, evidence-based resources for use across Europe. Table 1 summarizes these key characteristics and their implementation during the development process.

2.2 Study components and procedures

2.2.1 Outline of the co-creation process

The informational content was developed through a four-phase co-creation process: (1) identifying key topics, (2) creating preliminary content and evaluating it through focus groups, (3) revising the content and reviewing it through a Delphi study, and (4) finalizing the content for dissemination (Table 2).

Table 2. Phases of Co-Creation of the informational content.

Phase	Aim	Key activities	Participants	Output
1. Identification of key topics	Define content topics to be covered on the website	• Systematic reviews[9,10] • e-QuoL Needs Study[17] • Review PanCare website[16]	Research team	List of prioritized topics
2. Content creation and focus groups	Draft content and collect user feedback	• Systematic literature searches for topics identified in phase 1 • Draft content by experts • Readability check[23] • Focus groups with support network members	Experts and support network members	Revised draft content
3. Delphi study	Achieve expert consensus on content quality	• Iterative feedback rounds conducted using a survey, including options for open-ended responses	Experts and support network members (user panel)	Consensus-approved content
4. Finalization and dissemination	Translate, adapt, and publish	• Country-specific adaptations, including translation into multiple languages and the addition of country-specific resources • Integration into PanCare website	Research team, e-QuoL partners	Multilingual, web-based, informational content

The co-creation process involved support network members at multiple stages. First, the topics were informed by the information and support needs expressed by support network members in the European e-QuoL Needs Study.[17] Subsequently, support network members actively contributed to refining the preliminary informational content through focus groups, and their feedback was incorporated into revised versions before the content was reviewed by experts and support network members in the Delphi study. This iterative process ensured that the informational content was tailored to the needs of support network members while maintaining high scientific quality.[19]

The four-phase development process commenced in January 2024 and is expected to be completed in December 2027. At the time of writing, development of the preliminary informational content, participant recruitment, and data collection had been completed, while data analysis, finalization, and dissemination of the informational content are ongoing.

Phase 1: Identification of key topics

Phase 1 focused on identifying the main topics that should be covered in the informational content. Topics were selected based on systematic reviews on the information needs of support network members of CAYACS[9,10] and findings from the European e-QuoL Needs Study, which assessed needs across support network members from 19 countries.[17] To prevent duplication of information, existing content on the PanCare website was reviewed.[16] As the PanCare materials primarily target CAYACS, specific aspects relevant to support network members—such as understanding survivors' experiences, communicating about late effects, and providing adequate support[17]—were included to ensure the new content complements rather than replicates existing resources.

Phase 2: Content creation and focus groups

Phase 2 involved the development of preliminary informational content by experts in childhood, adolescent, and young adult (psycho-)oncology, including members of the Childhood Cancer Research team at the University of Lucerne and affiliated partners of the e-QuoL project. Sources included international guidelines (e.g., International Guideline Harmonization Group [IGHG][22]), literature reviews, peer-reviewed research, and clinical expertise from psychologists and healthcare professionals. To make sure all relevant literature reviews were included, systematic literature searches were conducted for each domain for which informational content was developed (**Appendix 1**).

The informational content was written in accessible language to facilitate understanding. To ensure readability, the Hemingway Editor tool was used, with a target readability grade of ≤9, reflecting the average adult reading level.[23] Content was developed in different formats (text, factsheets, brochures, and videos) and followed a standardized structure to promote clarity and consistency. Each section included a definition of the challenge, its prevalence, coping strategies, and additional resources. Once the preliminary drafts had been completed, focus groups with support network members evaluated the relevance, clarity, completeness, and helpfulness of the informational content.

Phase 3: Delphi study

In Phase 3, the revised content, based on focus group feedback, underwent consensus-based evaluation in a Delphi study to iteratively assess and improve its quality.[18] The content was evaluated by a panel of experts and support network members of CAYACS. During the Delphi process, revisions were made between rounds to incorporate panel feedback.

Phase 4: Finalization and dissemination

In Phase 4 (ongoing), the informational content will undergo final editing and country-specific adaptation, including translation into the relevant European languages and cultural validation. Initial translations will be generated using artificial intelligence (AI)-assisted translation and subsequently reviewed by native-speaking e-QuoL partners to ensure linguistic accuracy and cultural appropriateness.

Where necessary, country-specific adaptations will be made to reflect differences in healthcare systems, available resources, and cultural context. In addition, a dedicated "Resources per country" section will provide links to national information sources, organized by topic (e.g., follow-up care, patient organizations, and psychosocial support; **Appendix 2**). This section will be completed by e-QuoL partners from the respective countries.

Once finalized, the content will be hosted on the PanCare website[16] and made available in English and the languages of participating e-QuoL countries. Translations will be implemented in phases to support feasibility.

2.2.2 Focus groups

Aim

The aim of the focus groups was to gather end-user feedback on the relevance, clarity, completeness, helpfulness, and preferred format (e.g., text, factsheets, videos) of the preliminary informational content.

Participants

Eligible participants were English-speaking members of the support network of CAYACS (e.g., parents, siblings, partners) aged ≥16 years and residing in Europe (Table 3). CAYACS were defined as individuals diagnosed with cancer before the age of 25 years, who had completed treatment and were free of active disease. English proficiency was required because the preliminary informational content was developed in English and a shared language was necessary for the discussions. The minimum age of 16 years was selected because younger children and adolescents may have different needs and preferences regarding the presentation of information.

The final sample size was determined by data saturation, defined as the point at which no new insights emerged. As this was a qualitative study, no formal sample size calculation was performed.

Study procedures

Participants were recruited through large cancer survivorship platforms (PanCare,[16] Childhood Cancer International (CCI) Europe[24]). The e-QuoL partners shared the leaflets with patients and parents' organizations and hospitals in their respective countries. The leaflets were also distributed on the e-QuoL project website and via posts on LinkedIn.

Interested individuals registered either (a) by responding to an invitation from CCI Europe, which forwarded their contact details (name and email address) to the study team, or (b) by scanning a Quick Response (QR) code linked to a secure online registration form created in Qualtrics (Provo, UT).

Prior to participation, focus group members provided informed consent and completed a short questionnaire in Qualtrics (Provo, UT) on demographic and contextual characteristics (age, gender, country of residence, survivor's diagnosis and age at diagnosis, survivor's (neurocognitive) late effects, and follow-up care status). These characteristics were collected to describe the study sample. All data were collected in broad categories to ensure anonymity.

Focus groups were conducted online via Microsoft Teams and lasted approximately 90 minutes, each covering a maximum of three content domains. Participants received the preliminary content at least one week in advance for review.

Table 3. Overview focus group and delphi study participants.

Aspect	Focus groups	Delphi study
Study period	2 September 2025–16 January 2026	14 January 2026–30 April 2026
Target group	Support network members of CAYACS[a], e.g., parents, siblings, and partners	Experts (oncologists, psychosocial specialists, e-QuoL team members, support network members)
Eligibility criteria	≥16 years, English-speaking, living in Europe, interested in cancer-related information	≥16 years, English-speaking, living in Europe
Sample size	13 participants	52 participants
Recruitment	PanCare, CCI Europe, e-QuoL partners, patient and parent organizations, hospitals, social media channels	PanCare, e-QuoL partners, patient and parent organizations, hospitals, pediatric oncology working and research groups, social media channels
Language	English (shared discussion language)	English
Informed consent	Online via Qualtrics (Provo, UT)	Online via Qualtrics (Provo, UT)

Note: CCI Europe = Childhood Cancer International - Europe; CAYACS = Childhood, Adolescent, and Young Adult Cancer Survivors.[24]
[a]CAYACS were defined as individuals diagnosed before age 25 years who had completed treatment and were free of active disease.

At the start of each session, the procedure was explained and questions were addressed. Discussions focused on participants' perspectives on the preliminary content. Sessions were facilitated by a moderator and co-moderator using a structured topic guide (**Appendix 3**) containing facilitation recommendations, discussion rules, and structured open-ended questions and probes. Two participants who were unable to attend a scheduled focus group completed an individual interview using the same topic guide. All sessions were video recorded via Microsoft Teams to capture both verbal and non-verbal cues and allow accurate attribution of participants' comments.

Analysis

Focus group recordings were transcribed verbatim. Initial transcripts generated by Microsoft Teams were manually reviewed, corrected where necessary, and finalized. To enable revision of the informational content for the subsequent Delphi study, a preliminary analysis of the focus group feedback was conducted. The full qualitative analysis is ongoing and will use qualitative content analysis.[25] A deductive approach will be applied using predefined categories and subcategories based on the study aims (relevance, clarity, completeness, and helpfulness) and the structured topic guide (**Appendix 3**). Where necessary, additional categories will be developed inductively from the data. One researcher will code the transcripts, and a second researcher will review the coding. Any discrepancies will be resolved through discussion until consensus is reached. MAXQDA software (VERBI Software, Berlin, Germany) will be used to support the qualitative analysis. Quantitative questionnaire data will be analyzed using descriptive statistics in Stata (StataCorp LLC, College Station, TX, USA).

2.2.3 Delphi study

Aim

The aim of the Delphi study was to achieve consensus among experts and support network members on the relevance, clarity, completeness, and credibility of the developed informational content. Building on the revisions made following the focus groups, the Delphi study provided a structured expert review and consensus process to ensure the quality and credibility of the final informational content prior to dissemination.

Participants

Eligible participants were English-speaking experts, such as pediatric oncologists, psychosocial specialists, and researchers in the field, as well as representatives of the support network of CAYACS (e.g., parents, partners, siblings, and close friends aged ≥16 years) living in Europe (Table 4).

To account for potential attrition between Delphi rounds, we aimed to obtain at least six reviews for each informational content draft. As 15 informational content drafts were evaluated, this corresponded to a target of at least 90 completed reviews across all Delphi rounds.

Study procedures

Participants were recruited through the PanCare platform. In addition, e-QuoL partners distributed recruitment leaflets to patient and parent organizations and hospitals in their respective countries. Healthcare professionals and researchers were recruited through pediatric oncology clinical and research networks. Recruitment leaflets were also shared via the e-QuoL project website and LinkedIn.

Efforts were made to ensure a balanced mix of clinical experts, psychosocial professionals, and support network representatives in the panel. Participants received up to two reminder emails to minimize attrition between Delphi rounds. Response rates and attrition across Delphi rounds will be reported in the final study publication together with the results of the analyses.

Prior to participation, panel members provided informed consent and completed a short questionnaire on demographic and professional characteristics (age, gender, country of residence, role in relation to CAYACS, and, for professionals, profession and years of experience). All data were collected in broad categories to ensure anonymity.

The Delphi study was conducted online using the Qualtrics (Provo, UT) survey platform. Panel members received the informational content for review and were invited to provide feedback in iterative rounds. In each round, participants

Table 4. Overview of domains covered in the informational content.

Domain	Subdomain
Cancer-related health information	Cancer risk for family members, how to address potential risks, including genetic testing options
	Information on cancer recurrence and subsequent tumors (distinction between recurrence vs. subsequent tumors; prevention)
	Supporting CAYACS with late effects and talking about cancer-related challenges
Psycho-emotional consequences	Emotional and mental health (psychosocial challenges CAYACS face; mental health challenges in support network members; resilience)
	Coping (worry, anxiety, feeling down; uncertainty about CAYACS' future; fears about disability/deterioration; staying positive and finding meaning)
	Parenting a survivor and their sibling(s) (*parents only*)
Long-term follow-up care and surveillance (LTFU)	Long-term Follow-up (LTFU) (importance for early detection of late effects, frequency, supporting CAYACS with LTFU)
	Supporting CAYACS with their care (transition to adult health care; providing input during appointments; expressing concerns to healthcare providers)
Insurance and financial consequences	Financial and insurance consequences, right to be forgotten
Education and employment	Challenges for CAYACS (impact on education and employment): what is important to know for support network members
	Challenges for parents and strategies for coping and support
Services and finding support	Peer support (websites, finding others with similar experience, local support groups)
	Emotional support (how to find professional counseling/therapy)
	Practical support (transportation, accessibility, daily challenges)
Sexuality (partners only)	Changes in sexuality and relationships after cancer (impact of treatment incl. Fertility, libido, sexual relationship, coping strategies for partners, communication)
	Support and counseling for sexual concerns (where to seek help, counseling)

Note: These domains were included because most support network members reported needs in these areas in the e-QuoL Needs Study[17] or they were identified as relevant in systematic reviews.[9,10] The sexuality domain was added specifically because a substantial proportion of partners (47%) reported information or support needs in this area, and given the sensitivity of the topic, individuals may be more hesitant to seek information directly from professionals. CAYACS = Childhood, Adolescent, and Young Adult Cancer Survivors. LTFU = Long-term Follow-up.

rated the content and provided open-ended feedback using a questionnaire adapted from the MAPPinfo checklist.[26] The checklist, originally developed to assess the quality of health information materials, was simplified for use in the Delphi study and adapted to include psychosocial aspects relevant to support network members.

The questionnaire (**Appendix 4**) covered four domains: relevance for the target group, completeness of information, credibility, and clarity and presentation. Participants responded on a four-point scale (strongly disagree, disagree, agree, strongly agree). For each domain, an average score across all items was calculated for each panel member. Consensus was considered achieved when at least 75% of panel members had an average score > 2.5 on the 1–4 Likert scale (1 = strongly disagree, 4 = strongly agree).[27] When consensus was not reached, the informational content for that domain was revised based on participants' qualitative feedback and presented again in the subsequent Delphi round.

Analysis

Quantitative ratings from the Delphi questionnaire were analyzed using descriptive statistics (percentage agreement per round) in Stata (StataCorp LLC, College Station, TX, USA) to determine the level of consensus. A preliminary qualitative analysis of participants' comments was conducted to revise the informational content between Delphi rounds.

The full qualitative analysis is ongoing and will use qualitative content analysis[25] with predefined categories and subcategories based on the study aims (relevance, clarity, completeness, and credibility) and the Delphi assessment tool

(**Appendix 4**). Two researchers will independently code the qualitative comments and resolve discrepancies through discussion until consensus is reached. MAXQDA software (VERBI Software, Berlin, Germany) will be used to support the qualitative analysis.

2.3 Ethical approval and consent to participate

The project was approved by the Ethics Committee of the University of Lucerne, Switzerland (Number #2025–025, August 25, 2025). It complies with the Swiss Federal Act on Data Protection (235.1, June 19, 1992) and the Swiss Human Research Act (810.30, September 30, 2011).

Participation was voluntary, and informed consent was obtained electronically via Qualtrics (Provo, UT) prior to participation in the e-QuoL Needs survey, the focus groups, and the Delphi study. Participants received detailed study information outlining the project's purpose, procedures, voluntary nature of participation, data protection, and contact details of the research team.

Where applicable, participants aged 16 and 17 years provided their own electronic informed consent. This procedure was approved by the Ethics Board of the University of Lucerne for all study components described in the protocol. It was also in line with the age requirements for parental consent for children's participation in research in the countries where recruitment took place, as reported by the European Union Agency for Fundamental Rights (https://fra.europa.eu/et/publication/2019/child-participation-research).

The Ethics Committee of North-Western Switzerland confirmed that the Needs Study did not fall within the scope of the Human Research Act because only anonymized research data were collected. The focus groups did not include minors, and the Delphi study did not assess any medical information. Country-specific information on ethics approval dates and reference numbers, where applicable, is available in the Extended Data accompanying this study on Zenodo.[28]

The study involved minimal risk and did not include the collection of sensitive personal data. Focus group discussions focused on feedback regarding the informational content rather than participants' personal experiences. Some cancer-related material could nonetheless have elicited emotional responses. To minimize this risk, trained moderators facilitated the sessions, created a respectful environment, and monitored participants' well-being. Participants could skip questions or withdraw at any time without consequences. No financial compensation was provided.

All research data were anonymized prior to analysis. Identifiable information (e.g., consent forms and contact details) was stored securely at the University of Lucerne, separately from the research data. Video recordings of the focus groups will be deleted once the scientific publications have been completed. Transcripts, survey responses, and consent forms will be retained for 10 years after completion of the project. Results will be disseminated through peer-reviewed publications and scientific conferences.

3. Results

The proposed four-phase co-creation methodology is being implemented between January 2024 and December 2027 to develop informational content for support network members of CAYACS across Europe.

As part of Phase 1, the e-QuoL Needs Study, a large European study conducted across 15 countries, identified substantial unmet needs related to cancer-related health information, psycho-emotional care, surveillance, finances, education, and sexuality among support network members.[17] Based on the findings of this study and existing systematic reviews,[9,10] a list of topics was compiled (Table 4) excluding topics for which only a minority reported unmet needs (e.g., spirituality).

In Phase 2, informational content was drafted and reviewed through three online focus groups and two individual interviews involving a total of 13 support network members. The interviews were conducted with participants who were unable to attend a scheduled focus group and followed the same topic guide.

Phase 3 involved an international Delphi study with 52 support network members and experts. Consensus was reached in two rounds. All content drafts were reviewed by 6–10 reviewers each. The iterative co-creation process enabled systematic refinement of the informational content based on expert and end-user feedback.

At the time of writing, the final qualitative analyses are ongoing. Phase 4 is also ongoing and includes finalizing the informational content, translations, country-specific adaptations, and dissemination through the PanCare website.

4. Conclusions/Discussion

Support network members of CAYACS report substantial information and support needs across multiple domains, ranging from cancer-related health information to emotional support, follow-up care, education, financial issues, and sexuality.[9,10,17] These needs remain insufficiently addressed in current survivorship care, and there are inequalities in care across European regions.[11] By developing a central, online information resource covering multiple topics, this project directly addresses these gaps and provides practical, accessible resources for support network members of CAYACS. Making the informational content available in multiple languages and formats will further increase accessibility and promote equity in survivorship care.

A unique feature of this project is the co-creation process, in which support network members and experts collaboratively develop the informational content. This approach enhances its relevance, usability, and overall quality, while fostering trust and engagement among end-users.[19] The mixed-methods design, combining focus groups and a Delphi study, systematically integrates perspectives from multiple stakeholders.

As with any international initiative, several practical and operational challenges can be anticipated. First, informational content must be updated regularly to remain accurate and relevant as new knowledge emerges. To address this, we will establish a working group of international experts responsible for overseeing periodic updates. Second, translating the informational content into multiple languages is a time-intensive process; therefore, translations will be implemented in phases. Third, ensuring awareness and accessibility of the informational content across countries requires targeted dissemination strategies. Hosting the content on the PanCare website,[16] a widely recognized platform, will enhance accessibility. Healthcare professionals can play a key role by directing CAYACS and their loved ones to the website during consultations, and the information resource can be promoted through presentations at international conferences. Fourth, because participation in focus groups and the Delphi study requires English proficiency, participants are likely to have a higher education. To make the content accessible to a broad audience, it was written in clear language, at or below the average adult reading level, as assessed with the Hemingway Editor tool.[23]

Beyond its practical outcomes, this project contributes to scientific knowledge by documenting the process of co-creation and user-centered design in survivorship care. The lessons learned may inform future research and guide the iterative development of similar resources in other contexts and populations.

Ultimately, this project has the potential to strengthen survivorship care by addressing the information and support needs of CAYACS' support network members, an often overlooked yet vital component of CAYACS' long-term recovery and well-being.[21]

Author roles

Anne Maas: Conceptualization, Writing – original draft. **Valeriia Balaeva:** Conceptualization, Writing – review & editing. **Charlotte Demoor:** Writing – review & editing, Funding acquisition. **Hanne C. Lie:** Conceptualization, Writing – review & editing, Funding acquisition. **Jelena Roganovic:** Writing – review & editing, Funding acquisition. **Kristen E. Thompson:** Conceptualization, Writing – review & editing. **Katharina Roser:** Conceptualization, Writing – review & editing. **Gisela Michel:** Conceptualization, Writing – review & editing, Funding acquisition, Supervision.

Ethics approval and consent to participate

The project was approved by the Ethics Committee of the University of Lucerne, Switzerland (project number #2025–025, date August 25, 2025). All participants provided informed consent electronically via Qualtrics prior to participation. Participants aged 16–17 years provided their own electronic informed consent, as approved by the Ethics Board of the University of Lucerne.

Declaration of AI-assisted technologies in the writing process

During the preparation of this manuscript, the first author used ChatGPT (OpenAI, GPT-5.2) to support language editing and improve the readability and clarity of the text. After using this tool, the first author reviewed and edited the content as required. All authors reviewed the manuscript and take full responsibility for its content.

Availability of data and materials

The data that will support the findings of this study will be available from the corresponding author upon reasonable request. Requests for access to the data should be directed to the corresponding author at gisela.michel@unilu.ch. Access will be granted where this is consistent with participants' informed consent, ethical approval, and applicable data protection regulations.

Extended data

Extended data for this study are available on Zenodo: Extended data for: Co-Creation of Web-Based Informational Content for Support Network Members of Childhood, Adolescent and Young Adult Cancer Survivors: A Mixed-Methods Study Protocol of the e-QuoL Content Creation Project. https://doi.org/10.5281/zenodo.21718014.[28] The repository contains participant information sheets, informed consent forms, questionnaires, interview and focus group guides, Delphi materials, and additional supporting documents.

Data are available under the terms of the Creative Commons Attribution 4.0 International license (CC-BY 4.0).

Acknowledgements

This study will be conducted as part of the e-QuoL project. We thank the e-QuoL consortium (https://equolproject.eu/consortium/) for their contributions.

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